Patient Handout: Coping with Treatment Delays

Dear Patient,

You may experience treatment delays, especially if your course is prolonged. That’s normal. This handout reviews common questions and concerns to help you respond in helpful, hopeful ways.

What does a “delay” in treatment mean?
A delay occurs when we decide not to proceed with a treatment as scheduled. Our original treatment plan was based on…
• Years of research evaluating which dosages and timings give the best outcomes for patients with your type of cancer.
• The specifics of your cancer situation at the time.
• Your health at the time (e.g., your other medical conditions, weight, medications, etc.)
• Your values and priorities.

We aimed to follow the schedule as closely as possible, knowing that life events and changes in your condition might cause us to delay some treatments or even change the plan.

Why do delays happen?
Common causes of delays include…
• Low blood cell counts. Cancer treatments may cause low blood counts. The longer the course of treatment, the more likely that your body needs extra time to recover. Other factors, including other medications, may cause or contribute to low blood counts, too.
• Severe side effects. We don’t want severe side effects hampering your recovery, such as by interfering with nutrition or sleep, or making it too difficult to live your life.
• Illness from other causes. If recovering from an injury or illness (e.g., pneumonia; surgery), your body may need more time before it is strong enough to handle anti-cancer therapy.
• Major life events. When meaningful or once-in-a-lifetime events arise, it may be more important to attend them, especially when the downside of delaying treatment is relatively small.

How important is staying on schedule?
Very important. That said, it is more important…
• To prevent complications that risk your life or decrease the chance of the best outcome.
• To participate in special occasions when treatment delays would make little difference.

Our overriding goals are to achieve the best outcome for you and to help you live your best life under the circumstances. If something comes up (as often happens), delaying treatment may be the safe and wisest course of action. As an analogy, imagine mapping out the best route to get to a party. If you come across a flooded road, you take a detour even when that delays your arrival. Or, if you come across a stunning field of flowers, you might stop to take some pictures.

What does a delay mean for your recovery?
It may mean nothing. Many factors impact each patient’s outcome, including new therapies that become available. We can discuss with you what your delay might mean.

What if you feel distressed by the delay?
Patients may feel any combination of disappointment, anger, frustration, increased anxiety, relief, or other emotions. Common reactions include…
• “I geared up emotionally…for ‘nothing.’”
• “Cancer is controlling my schedule…my life!”
• “Now I won’t finish by (date), which ruins my plans.”
• “I’m worried about more delays.”
• “I’m afraid that my body is getting sicker and weaker.”
• “I did everything right. I feel cheated…powerless.”
• “I want to feel hopeful, but this makes it harder.”

We realize the burden of undergoing treatment, with “costs” that add up: paying the expenses of travel, childcare, and up favors from friends and work “sick days”; missing events you wanted to attend—plus the need for rest, waiting time, and other inconveniences of treatment days. Consequently, a delay can trigger resentment of having made sacrifices “for nothing,” knowing you may have to sacrifice again when you can receive treatment.

How can you minimize the distress?
• Express grief over the losses. Your losses are real, even when “small” in the grand scheme of things. Find safe places to express the normal—and healing—reaction. (See the patient handout, Honoring Grief, https://tinyurl.com/OTHonoringGrief)
• Keep perspective. Step back and think about the big picture. A delay is a speed bump—not a major setback. In or out of treatment, you have today. How can you make it the best it can be?
• Take advantage of the break from treatment and its side effects. Find ways to get the most out of the unscheduled time.

If low blood counts or severe side effects cause a delay, is that your fault?
No. Treatment that kills cancer cells is hard on healthy cells, too. After a treatment, your body may need extra recovery time before it is ready to work with the next treatment against the cancer. It’s the same idea as when an elite athlete needs recovery time after a big competition before resuming intense practice or competition.

Is it okay to be happy about a delay?
Yes, if you don’t cause a delay on purpose. The break from treatment feels good. It’s fabulous to do something fun or meaningful that you expected to miss. For people feeling a bit anxious about completing treatment, delaying that transition brings relief. For those in chronic treatment, the delay gives a welcome break during which they can recharge physically and emotionally.

What if you feel ambivalent—or guilty—about delaying for social reasons?
Here’s why you can let those feelings go: We weighed the risks and benefits for you before agreeing to reschedule your next treatment. Rest assured: We are not taking chances or giving up. If ever a delay carries great short-term risks or hurts your chance for recovery, we will tell you directly.

How can we help prevent further delays?
• Medications. We may adjust your cancer therapy and/or your other medications. Please keep us updated with a list of all your medications, including over-the-counter therapies.
• Consultations. We may discuss whether consultations with other professionals might help optimize your diet (nutritionist), conditioning (physical therapist), sleep (counselor or sleep specialist), or other aspect of health.
• Well-being. Participation in a support group or one-on-one counseling may help you stay in a good frame of mind for pursuing health-promoting measures and dealing with the emotions triggered by delays.

Meanwhile, we will make every effort to minimize scheduling glitches. You help us when you ask about when and where you need to go for tests, consultations, and treatments. Please notify us if scheduling is not proceeding smoothly. Let’s work together to minimize delays, adjust course as needed, and look forward with hope of the best possible outcome.